

Bill #369 March 15, 2012

David Jacobs, Executive Director

Rhonda Wirth, Early Childhood Center Director

Alyssa Temkin was a student in the pre-school at the Mandell Jewish Community Center for three years. A child with Glycogen Storage Disease, Alyssa required observation, frequent blood testing and feeding at regular intervals. Her mother, Gayle, arranged with the JCC to remain on the premises while Alyssa was at school and to periodically enter the classroom to take care of her daughter's needs. Eventually, Alyssa's trained caregiver assumed responsibilities for the testing and feeding. This caregiver is well known to Alyssa, comfortable around young children and most importantly, directly trained by Alyssa's specialist. This arrangement was seamless, and was universally supported by the school, teachers and other parents.

More importantly, it provided a child with the opportunity to have a typical educational experience and allowed a parent to be in control of how her daughter's unique medical needs were handled. This situation also helped the teachers in the classroom, as well as the other parents and students, to feel comfortable. Alyssa's caregiver was dressed in street clothes and not a clinical coat, which sometimes worries children and parents.

Closing the door to Alyssa by not permitting her mother or her mother's surrogate access to the classroom was unthinkable. The most important priority was for Alyssa to be safe, to have a typical classroom experience without being set apart from her peers.

Parents are their children's strongest advocates and supporters. If those in the medical field determine that a solution to support the situation is medically feasible and proper, the State should allow parents to help school environments help their child. We strongly encourage the State of Connecticut to enact legislation that would allow children with feeding tubes to be supported by their parents or their parents' surrogates while participating in the usual classroom experiences.